

PEDIATRIC RESEARCH AND INNOVATION: ETHICAL AND SOCIAL CONSIDERATIONS

International Conference, March 23rd -24th 2023

Faculty of Medicine, University Autonomous of Madrid (UAM)

DAY 1 : THURSDAY MARCH 23RD

9h00-9h15 Welcome guests

9h15-10h00

40 years of Clinical Research Ethics Committees in Spain.

Jesús Frias, Prof. Emer. of Pharmacology, University Autonomous of Madrid (UAM).

10h00-11h30

SESSION 1 : BIOETHICAL PERSPECTIVES ON PEDIATRIC RESEARCH.

Moderator: Santiago Rello Varona, International Research Funding Officer IdiPaz.

What Do We Owe Future Adults? Rights, Interests, and Future Autonomy in Pediatric Health Research.

Jeremy Garrett, Research Associate in Bioethics, Children's Mercy Kansas City Hospital.

Feminist Perspectives on Pediatric Research.

Leslie McNolty, Adjunct Asst. Prof. University of Missouri – Kansas City School of Medicine.

The ethics of mental health research with young people: some reflections.

Paolo Corsico, Research Associate at The University of Manchester, UK.

Ethics of Experimental Neuromonitoring and Neurostimulation in Pediatrics.

Marcello Ienca, Assoc. Prof. at the Technical University of Munich,

Ambra d'Imperio, Attending in Consultation Psychiatry Hospital University of Geneva,

Georg Starke, postdoctoral researcher at the College of Humanities at EPFL (Swiss Federal Institute of Technology Lausanne).

11h30 –12h00 Coffee Break

12h00-13h00

Recognizing young people as moral agents: A childhood ethics perspective on the meaningful participation of young people in research. [online presentation]

Franco Carnevale, Professor, McGill University, Montréal.

13h00 –14h30 Lunch Break

14h30 –16h00

SESSION 2 : HUMANITIES AND SOCIAL SCIENCE STUDIES ON CHILDREN AND MEDICINE.

Moderator: Maria Cristina Murano, MSCA Fellow at Idipaz Madrid and SPHERE Paris.

The Religious/Secular Dichotomy and the Problem of Pediatric Cancer.

Anthony Gerard Wright, Asst. Prof., Dept. of Childhood Studies, Rutgers University – Camden, New Jersey.

Children's participation in their own cancer treatment: an anthropological– historical perspective. [online presentation]

Ignasi Clemente, Asst. Prof. Dept. of Anthropology, Hunter College, City College of New York.

Child vulnerability and autonomy: some ethical challenges.

Mar Cabezas, Assoc. Prof. of Moral Philosophy, University of Salamanca.

What is at stake when treating doesn't actually mean healing? The case of the hemolytic disease of the newborn. [online presentation]

Nathalie Sage Pranchère, Researcher in History, CNRS, SPHERE Research Unit, Paris.

16h00–16h30 Coffee Break

16h30–17h30

The role of the Young Person's Advisory groups in a children's hospital and in the European research ecosystem.

Sofia Junquera, Jordi Cruz, Jan Balayla y Queralt Sauri, KIDS Barcelona.

Begonya Nafria, Patient Engagement in Research Coordinator, Hospital Sant Joan de Déu de Barcelona.

17h30–19h00

SESSION 3 : RESEARCH ETHICS AND PARENTS' PERSPECTIVE.

Moderator: Alberto Borobia, Assoc. Prof. Clinical Pharmacology Department UAM, Manager of the Clinical Trials Unit HULP.

Ethical considerations in pediatric research: the ethics committee view.

Manuel Espinoza Vega, MD, Pediatric Surgery, Hospital Niño Jesús Madrid.

Research with minors from an ethics committee.

Txetxu Ausín, Tenured Scientist at the Institute for Philosophy and Dir. of the Applied Ethics Group, CSIC Madrid, President of the CSIC Ethics Committee.

CareInTrials. Conducting empirical philosophy research in a Clinical Trials Unit.

Maria Cristina Murano, Marie Skłodowska-Curie Fellow at Idipaz Madrid and SPHERE Research Unit (CNRS–University Paris Cité)

Beyond science.

Rodrigo Laña, DMD, MA, father of twins with cerebral palsy and epilepsy, activist for medical cannabis access in Colombia.

20h00–23h00 Dinner

DAY 2 : FRIDAY MARCH 24TH

10h00–11h30

SESSION 4: CITIZEN'S PARTICIPATION IN RESEARCH: THEORY AND PRACTICE.

Moderator: Santiago Rello Varona, International Research Funding Officer IdiPaz.

Participate for what? Insights from Surprise and Tresca projects.

Vincenzo Pavone, Tenured Scientist and Dir. of the Institute of Public Goods and Policies, CSIC Madrid.

Participation as mainstreaming governance paradigm: truth or trick?

Barbara Biglia, Agregada Serra Hunter (Assoc. Prof.), Dept. of Pedagogy, University Rovira i Virgili, Tarragona.

Trial participation and research literacy.

Patrick Miqueu, Coordinator of Research Promotion & Patient Collaborations at Institute Jules Bordet, Brussels .

Making participation work for children and young people.

Jennifer Preston, Senior Patient and Public Involvement Manager, University of Liverpool, NIHR Alder Hey Clinical Research Facility.

11h30–12h00 Coffee Break

12h00–13h00

Patient participation in trials: arguments for and against.

David Teira, Prof. of Philosophy, Dept. of Logic, History and Philosophy of Sciences, National University of Distance Education (UNED) Madrid,

Aube Bandini, Asst. Prof. of Philosophy, University of Montréal.

13h00 –14h30 Lunch Break

14h30–16h00

SESSION 5: CONTEMPORARY AND FUTURE ETHICAL CHALLENGES IN HEALTH RESEARCH.

Moderator: Maria Cristina Murano, MSCA Fellow at Idipaz Madrid and SPHERE Paris.

Conflict of interest in biomedical research [online presentation].

Boris Hauray, Researcher in Sociology at the National Institute of Health and Medical Research (Inserm) Paris.

Genomics and pediatric oncology: which ethics dilemmas for kids, parents and professionals?

Sandrine de Montgolfier, Assoc. Prof. of epistemology and biomedical ethics, Dir. of the Excellence Research Chair "Health democracy and patients' empowerment" Aix Marseille University– Sesstim.

Are puberty blockers experimental treatment?

Simona Giordano, Prof. of Bioethics, Centre for Social Ethics and Policy, The University of Manchester Law School, School of Social Sciences.

Limited Evidence based and consequences for clinics.

Nicolas Foureur, Dir. of the Center of Clinical Ethics of the Greater Paris University Hospitals (AP-HP), Paris.

16h00–16h30 Coffee Break

16h30–17h00 Concluding session

Discussion and conclusion of the conference in English.

The following session will be entirely in Spanish to facilitate patients' participation.

17h00–18h30

MESA REDONDA: EL EQUIPO DEL HOSPITAL UNIVERSITARIO LA PAZ EN DIÁLOGO CON LOS PACIENTES.

Moderadora: Paloma Moraga Alapont, Gestora de Ensayos Clínicos y Proyectos internacionales UCICEC.

Unidades de Soporte a la Investigación Clínica en hospitales de tercer nivel: el ejemplo de la UCICEC en el Hospital La Paz.

Alberto Borobia, Prof. Asociado CC Salud de Farmacología UAM, responsable UCICEC-HULP.

Papel de la enfermería de investigación en el desarrollo de ensayos clínicos pediátricos.

Vega Mauleón Martínez, Enfermera UICEC-HULP.

Medicina personalizada en oncología pediátrica.

Paula Valle Simón, Gestora de Ensayos Pediátricos UICEC-HULP, estudiante de Doctorado UAM.

Presentación de los resultados preliminares del estudio CareInTrials.

Maria Cristina Murano, Becaria Marie Skłodowska-Curie, Instituto de Investigación Hospital Universitario La Paz (IdiPaz) y Unidad de investigación en Ciencia, Filosofía, Historia (SPHERE), CNRS-Universidad París Cité.

Link to the Online Event



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Funded by
the European Union

Conference Host:



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de Madrid



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